

For Immediate Release

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**REQUIRING PHRS TO BE HIPAA-COMPLIANT PERPETUATES A BIG LIE:  
THAT HIPAA PROTECTS PRIVACY**

**Patients should be cautious about using PHRs, relying on HIPAA offers a  
false sense of security.**

Austin, Texas -- Today the [New England Journal of Medicine](#) published multiple articles on Personal Health Records (PHRs). The [New York Times](#) also highlighted the warnings of two of the authors of one of the NEJM articles, Drs. Mandl and Kohane, regarding PHRs not being covered by the Health Information Portability and Accountability Act (HIPAA) ("Warning on Storage of Health Records," *New York Times*, by Steve Lohr, 4/17/08). Each piece perpetuates a very dangerous and seldom challenged lie: that HIPAA protects our privacy.

Contrary to popular belief, the "P" in HIPAA does not stand for "privacy." Rather, HIPAA allows millions of healthcare businesses to snoop in our personal health records without our permission for "treatment, payment and operations" (TPO), which allows data mining, marketing and the sale of our electronic records.

Who decides when Americans' health data can be used? Those holding the data decide.

We cannot refuse access. No audit trails exist to prove who uses our sensitive information. There is no notice of access to our personal health information, no audits trails of disclosures, and there is no appeal process. Extending HIPAA to cover PHRs simply expands this massive privacy loophole and ensures PHR records can be data mined.

PHRs could very well open patients up even further to marketing, false advertising, fraud and perhaps more importantly, job and credit discrimination. We should be very careful and cautious about participating in any PHR. Many PHRs don't even post a privacy policy and the most common business model is selling your personal health information.

Important Considerations Patients Should Ask of a PHR:

- Does the PHR provider own rights to your information?
- Does the PHR provider have the right under its "agreements" to sell or share your information?
- What security does the PHR provide?
- What physical and technical measures are in place to prevent identity theft?
- How do you authorize access to the information? If it does not require more than a password, say "**no thanks**".
- Don't even think about using a PHR offered by an employer or insurer. These are the last people you want to share all your personal health, eating habits and daily activities with.

The only current federal law that governs PHRs offered to the public is the Federal Electronic Communications Privacy Act. The ECPA prohibits publicly-available PHR systems from releasing information to private parties without the consent of the account-holder and trumps the data mining allowed by HIPAA.

This summer Patient Privacy Rights will roll out a new service for patients that will provide an easy to understand explanation and grade (A-F) of a variety of PHR privacy policies. In the meantime, you should proceed with caution. A PHR that is "HIPAA-compliant" can own your information, sell or share your information, and have weak security. It would be a grave mistake to trust these HIPAA compliant PHRs. Promising to comply with HIPAA is as meaningless for protecting privacy as a snake's promise not to bite.

### ***About Dr. Deborah Peel and PatientPrivacyRights.Org***

Patient Privacy Rights is the nation's health privacy watchdog led by consumers and patients based in Austin TX. The mission of Patient Privacy Rights is to ensure that Americans control all access to their health records.

Dr. Peel, Founder and Chair of Patient Privacy Rights learned first hand about the importance of health privacy throughout her thirty-plus years as a practicing psychiatrist and is known for her straightforward and fiery advocacy. Patient Privacy Rights and Dr. Peel earned the attention of Congress in 2006 by working cooperatively to form the bi-partisan [Coalition for Patient Privacy](#). The Coalition includes nearly 50 organizations from across the political spectrum, including the Family Research Council, the Electronic Privacy Information Center, and the ACLU.

In 2007 Dr. Peel was named #4 of the [100 Most Powerful People in Healthcare](#) by Modern Healthcare magazine.

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